

**PRIORITIZATION OF DATA NEEDS FOR STATE ENCOUNTER DATA SETS FOR
PUBLIC HEALTH AND RESEARCH APPLICATIONS**

**A SUMMARY REPORT TO THE
PUBLIC HEALTH DATA STANDARDS CONSORTIUM**

**Prepared by the National Association of Health Data Organizations (NAHDO)
November 5, 2000**

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PRIORITIZATION OF DATA NEEDS FOR STATE ENCOUNTER DATA SETS FOR PUBLIC HEALTH AND RESEARCH APPLICATIONS

EXECUTIVE SUMMARY

With the advent of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), opportunities to improve the standardization of discharge databases have emerged. HIPAA led to the establishment of the Public Health Data Standards Consortium--a partnership of public health and research working together to understand and utilize the standards setting process as outlined in HIPAA¹. This document is the final report on one of the projects undertaken by the Consortium, entitled “*HIPAA Inpatient State Encounter Data Practices and Priorities Project.*”

BACKGROUND

The Public Health Data Standards Consortium

On November 2-3, 1998, the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention, in conjunction with the Agency for Healthcare Research and Quality (AHRQ) and the National Committee on Vital and Health Statistics (NCVHS), convened a workshop on "The Implications of HIPAA's Administrative Simplification Provisions for Public Health and Health Services Research." Among the outcomes of the workshop, participated in by 85 leaders in health statistics, research, and informatics, was a consensus recommendation for establishing a consortium to organize the public health and health services research communities on data standards issues. This consortium would serve as a mechanism for ongoing representation of public health and health services research interests in HIPAA implementation and other data standards setting processes.²

The Public Health Data Standards Consortium was officially established and held its first meeting on January 24-25, 1999, in conjunction with the annual meeting of the National Association of Health Data Organizations (NAHDO). The Consortium adopted a three-fold mission:

- (1) Improve the health and health care of the population through improved information by expanding involvement in existing health data standards and content organizations.
- (2) Facilitate the use of existing standards and the development of new data standards for public health and all areas of health services research.
- (3) Educate the public health and the health services research communities about HIPAA and other health data standards issues.

Many important activities continued through 1999 and into 2000 for the Consortium. The National Uniform Billing Committee and National Uniform Claim Committee both approved Consortium representation on their respective committees. In September 1999, NCHS contracted with NAHDO to assist in identifying the priority encounter data elements that are most urgent to the needs of public health and health services research. This report summarizes the activities conducted under this project, the processes followed, the outcomes achieved, and the recommendations offered.

Objectives of the Project

The *HIPAA Inpatient State Encounter Data Practice and Priorities* study is intended to provide planning and educational direction to the educational activities of the Consortium and serve as the basis for the development of a Consortium work plan. The project was composed of two components: education, and data element prioritization. The objectives are described below.

Education

- Educate Consortium members about the standards setting process and models in practice by ANSI ASC X12 and HL7.
- Educate the industry and national Standards Development Organizations (SDOs) about the need for uniform data for public health and research purposes and the value of these data to the industry and the public.
- Promote the use of standards in public health, using existing Health Level 7 (HL 7) or ANSI X12N standards where applicable and encouraging participation in the standards process where current standards do not meet public health needs.

Prioritization

The objective of the prioritization study was to evaluate data elements commonly collected by states that are directly related to policy analysis and public health surveillance at the state level. The study included those elements that states said they would continue to collect even if they were excluded from HIPAA Administrative Simplification X12N core standards³. By working to solve concrete and defined data needs in a collaborative process, a positive outcome of this study has been to lay the foundation for future, more challenging standards initiatives.

The study's purpose was to prioritize the common data elements most needed for improved health information for public health and research. The scope of this study was limited to statewide encounter data systems, recognizing that the data needs for public health and research go well beyond administrative data sets.

Significance of the Project

Discharge data systems are becoming an important component of state and national health data systems. Over forty states collect inpatient discharge data⁴, which provide information about the patterns of care, the health burden, and the costs associated with major morbidity. Despite the limitations, large administrative data sets are used to assess issues of health care access, cost, and quality⁵. The systematic collection of discharge data offers a relatively uniform and cost-effective source of health services.

For the purposes of this study, discharge data are defined as a collection of demographic, clinical, and billing data reported for all patients admitted as an inpatient or outpatient to a health care facility.

Because discharge data systems are derived from the UB92 or other industry standards, the challenges and opportunities posed by HIPAA will affect these data systems immediately. The Consortium is concerned with HIPAA's impact on statewide encounter data systems and believes that experiences and lessons learned with discharge data can be transferred to other major health data sets. State and local public health entities are uncertain about the affect on major health data systems. Learning how the HIPAA standards process works is an important first step in reducing the uncertainty and assuring that the public health information infrastructure is maintained and improved.

Project Activities, October, 1999-October, 2000

The activities undertaken during the year covered in this report revolved around three areas: (1) Education and Outreach, (2) Data Collection and Analysis, and (3) Feedback Processing and Consensus Building. Each area is briefly described below.

Education and Outreach

A national conference call was held December 7, 1999 to address HIPAA implementation and the standards process and data standards. The teleconference marked the beginning of the educational and outreach process and provided an opportunity to begin gathering information from states about state-unique fields. Many of these participants were from state Medicaid agencies eager to learn about HIPAA implementation issues. (Unlike public health, which is largely exempt from many HIPAA Administrative Simplification provisions, Medicaid agencies must comply).

In recognition of the important role of education in the Consortium's goals, a standing Education Work Group was established at the March 21, 2000, Steering Committee meeting to develop and implement an educational strategy for the Consortium.

Data Collection and Analysis

Three data sources were used for the project:

1. The Healthcare Cost and Utilization Project's 1998 Statewide Encounter Data Availability Inventory (HCUP Partners Inventory) conducted by the National Association of Health Data Organizations (NAHDO) and the MEDSTAT Group in 1999 for the Agency for Healthcare Research and Quality (AHRQ).
2. The 1998 NAHDO Administrative Simplification Committee Survey of State Data Agencies, conducted by NAHDO staff and the Minnesota Health Data Institute.
3. Interviews conducted with state health data organization staff, late 1999

Consensus-building and feedback

NAHDO presented its preliminary findings at a meeting of the Consortium Steering Committee on March 21, 2000. Several work groups were established to address the data elements ranked of highest priority by meeting participants. The Work Groups assisted NAHDO in its current NCHS study, and developed the business cases for requesting specific data elements be added to the

national HIPAA Standards and Implementation Guides. The meeting generated the commitment by organizational members to each name a Principal Member and an Alternate to the Consortium's Steering Committee; a Planning Group also was established.

Findings were presented to the PHDSC at its March 21, 2000 meeting in Washington DC. Discussion and feedback were integrated into the preliminary report and shaped the final recommendations.

FINDINGS AND OUTCOMES

Initial List of Data Elements Considered for Prioritization

Based on the results of the NAHDO Survey, the HCUP Inventory, and interviews with selected state agency representatives, NAHDO identified twenty-two non-ANSI X12N 837 and high-priority data elements collected by statewide discharge data systems and grouped these data elements into domains or categories (Table 1).

Table 1: NON-X12N 837 and HIGH-PRIORITY DATA ELEMENTS COLLECTED BY STATES, 1998

Patient Demographics	Patient Status Variables	Clinical Variables	Linkage Variables	Financial Variables	Other Variables
Race and Ethnicity	Present on Admission Indicator	Number of E-codes	Unique Patient ID	Payer Type	Patient Consent on Immunization Record
County Code	Do Not Resuscitate	Pharmacy Values	Physician ID	Total Provider Paid Amount	Observation Days
Marital Status		Gestational Age/newborn	Mothers Medical Record Number on newborn record		
Patient Living Arrangement	Patient Functional Status	Birthweight/newborn record			
Education		Admitting vitals	EMS Run Number/record		
Occupation					

- These data elements were cross-walked to the 837 X12N Implementation Guide (version 4010). NAHDO then obtained case study and anecdotal information about these priority data elements from a cross-section of states collecting these elements. These states were asked about the method of data collection (voluntary or mandated), year first collection, reporting compliance, barriers to the collection of the data element, and how the data element is used.

NAHDO presented preliminary recommendations for priority action to the PHDSC at its March 21, 2000 meeting in Washington D.C.:

Data elements contained in the X12N Implementation Guide promoted for state collection

Present on Admission Indicator (promote collection by states)

Birthweight on Newborn Records (promote collection by states)

Race and Ethnicity (development of business case for inclusion into X12N standards and promote collection by states)

Data elements for PHDSC Action

Principal External Cause of Injury Code (business case development for expanding the number of E-codes)
Type of Payer (review of the existing X12N typology for public health/research applications)
Mothers Medical Record Number on Newborn Record (business case development for inclusion into 837 Core Data Standards)
Do Not Resuscitate (business case development for inclusion into 837 Core Data Standards)
County Code (business case development for inclusion into 837 Core Data Standards)

Data content issues, more study needed

Pharmacy Data/Values
Patient Demographic Data (Marital Status, Education/Income/Occupation Patient's Relationship to Subscriber (as proxy measures for patient living arrangement)
Patient Functional Status
EMS Run Number with Emergency Department Encounters
Patient Consent for Immunization Encounters
Observation Days

Data elements likely to be addressed by federal regulations

National Provider ID
(Health) Plan ID

Priority Data Elements for Standardization

After PHDSC discussion, consensus was obtained and the following data elements were selected, in order, by majority vote, as priorities for standardization. PHDSC ad hoc work groups were also established to develop a business case for specific data elements. The list of priority data elements and the Workgroup charges were as follows⁶ (citation from minutes of PHDSC meeting):

- E-codes (accommodated by 837) – This Work Group will develop justification and recommendations for expanding the collection of External Cause-of Injury Codes in the 837.
- Payer Type (within 837) – This Work Group will develop justification and recommendations for modifying and expanding the payer types currently collected in the 837.
- Mother's Medical Record Number (not within the 837) – This Work Group will develop justification and recommendations for collecting the Mother's Medical Record Number in the 837 for the Newborn to facilitate linkage of mother and newborn encounter records.
- Readmission or Repeat Admissions (not within the 837) – This Work Group will explore options and develop justification and recommendations for collecting information in the 837 concerning readmissions or repeat admissions to the hospital.
- Individual ID (accommodated by 837) - This Work Group will explore options and develop justification and recommendations for collecting a unique individual identification number in the 837.
- Source of Admission (within the 837) - This Work Group will develop justification and recommendations for modifying and expanding the sources of admission currently collected in the 837.

- Provider ID (NPI) (accommodated by the 837) – This Work Group will explore the ability of the National Provider ID System, proposed by the Department of Health and Human Services in a Notice of Proposed Rulemaking, to adequately enumerate all providers to meet the needs of public health and health services research and will make recommendations.
- County (accommodated by the 837) – This Work Group will explore the ability of the 837 to collect county of patient and will develop justification and recommendations.
- Patient Functional Status (condition indicators in 837) – This Work Group will explore the desirability and feasibility of collecting functional status in the 837. It will coordinate with a similar exploration being undertaken by the National Committee on Vital and Health Statistics Subcommittee on Populations.

Emerging also from the discussion was a consensus recommendation that the Consortium play a role in educating the states regarding the need for, and benefit of, standards, the present content of the 837, and the need for work on closing the many data gaps for adequate and accurate health information. Therefore, a standing **Education Group** was established to address such topics as education, communication, public relations, HIPAA implementation, technical assistance, and user-friendly data dictionaries.

Specific Recommendations and Next Steps⁷

The following four sections show a composite of the primary findings of this project. Each section is fully discussed in the body of the report including recommendations, current implementation status, and suggested next steps for each data element. Additionally, a matrix, Attachment A, shows each data element, the number of states collecting it, an indicator of whether it's an NCVHS core data element, and the existing national definitions. The recommendations are grouped as follows:

Priority Data Elements Recommended for Consortium Action

External Cause of Injury Coding, Place of Injury field for primary cause of injury
Source of Payment (i.e. Payer Type or Health Plan)
County Code
Race and Ethnicity*
Mother's Medical Record Number**

*approved for inclusion in next X12N 837 Implementation Guide

**approved for inclusion into X12N standard

Priority Data Elements with Unresolved Issues Needing Further Study

External Cause of Injury Coding, Adverse Effect of Medical Treatment
Source of Admission
Patient Demographics
 Patient Marital Status
 Patient Living Arrangement
 Current or Most Recent Occupation/Industry
Patient Functional Status
Readmission Indicator
Do Not Resuscitate (DNR) indicator
Gestational age on newborn record

Education of State Health Data Agencies to Promote Adoption in State Practice (837 institutional guide)

Mothers Medical Record Number on newborn record
Race and Ethnicity fields
Present on Admission Indicator
Birthweight of newborn

Consortium Action Determined Following Release of Final Federal Regulations

Plan ID
Unique Patient Identifier
Medicaid Provider Identifier Number

PRELIMINARY PROJECT EVALUATION

Early Successes

Two of the study objectives were achieved early in the course of this project: 1) education of public health about the standards setting process and 2) utilizing the X12N process to include race and ethnicity in the Demographic segment of the X12N Implementation Guide (version 4031) for Institutional 837 claims.

- The December 7, 1999 national HIPAA teleconference was an overwhelming success with more than 100 participants, many of whom continue to participate in follow-up discussions on the NAHDO Administrative Simplification Listserv.
- Race and ethnicity were the first data elements to be tested through the Consortium process and it demonstrated the power of combining a strong business case with communication between Consortium members. On March 11, 2000, Dr. Bill Braithwaite (DHHS) successfully made the case to the X12N Task Group 2 and Workgroup 2 for the inclusion of the expanded codes for Race and Ethnicity in the X12N Implementation Guide. Key to the business case, was the fact that 27 states currently collect race/ethnicity with their discharge data. A similar success was realized when Mother's Medical Record Number on the Newborn Record was successfully forwarded through the X12N Workgroup process.

Lessons Learned:

- States will need education and technical assistance to make the transition to ANSI X12N standards and will benefit from adopting these uniform and expanded standards
- The Public Health Consortium is an effective mechanism for coordinating and facilitating the national standards setting process
- Future standards studies should assess data needs for performance measurement and policy

Limitations:

The scope of elements studied was limited to those data elements most commonly collected in state discharge data systems. Many important data needs were not addressed, such as clinical data

elements used in performance measurement. For example, the Healthplan Employer Data and Information Set (HEDIS) defines performance measures that are derived from both administrative and clinical data systems. Adding key elements to X12N data standards may significantly lower the cost to report HEDIS by eliminating or reducing the need for abstracting information from the medical record (e.g. Beta Blocker with Acute Myocardial Infarction encounters).

Acknowledgements

NAHDO would like to thank Marjorie Greenberg, Hetty Kahn, and Suzie Burke-Beebe, NCHS for funding and guiding this study and acknowledges the contributions of the following: the Agency for Healthcare Research and Quality (AHRQ) for permitting the use of the information gathered in the 1999 Healthcare Cost and Utilization Project (HCUP) Partners Inventory; the Robert Davis, New York Department of Health; Jan Root, the Utah Health Information Network (UHIN); Walter Suarez, the Minnesota Health Data Institute (MHDI), and many other NAHDO members who contributed to the content of this study.

¹ The Administrative Simplification (AS) provisions of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) are intended to reduce the costs and administrative burdens of health care by making possible the standardized, electronic transmission of many administrative and financial transactions that are currently carried out manually on paper. See <http://aspe.hhs.gov/admsimp/Index.htm> for details.

² Public Health Consortium Fact Sheet, National Center for Health Statistics of the Centers for Disease Control and Prevention, 1999

³ National Association of Health Data Organizations (NAHDO) Administrative Simplification Survey of States, 1998.

⁴ Healthcare Cost and Utilization Project (HCUP) 1999 Partners Inventory, Agency for Healthcare Research and Quality (AHRQ)

⁵ Elixhauser, A., “The Importance of Administrative Data Sets for Public Health and Research”, 1998.

⁶ Minutes of meetings of PHDSC workgroups.

⁷ In all these recommendations, NAHDO assumes that the PHDSC will collaborate and use a consensus process to forward standards according to the national process outlined in HIPAA:

The Department of Health and Human Services (DHHS) has named the Designated Standard Maintenance Organizations (DSMOs). These organizations maintain standards for health care transactions adopted by the Secretary, and receive and process requests for adopting a new standard or modifying an adopted standard. In the case of a standard that has been developed, adopted, or modified by a standard setting organization (SSO), the SSO is to consult with the above-named groups during such development, adoption, or modification. In the case of any other standard, the Secretary is required to consult with each of the above-named groups before adopting the standard and must also comply with the provisions of section 1172(f) of the Act regarding consultation with the National Committee on Vital and Health Statistics.

These DSMOs include the following:

- Accredited Standards Committee X12.
- Dental Content Committee of the American Dental Association.
- Health Level Seven.
- National Council for Prescription Drug Programs.
- National Uniform Billing Committee.
- National Uniform Claim Committee.